To the Commissioners,

I would like to thank the Productivity Commission for undertaking an inquiry into the Life-time Care and Support Scheme for people with a disability.

My name is Jess and I have a condition called Transverse Myelitis. Below I have outlined my own situation and based on some of my experiences as a person receiving a range of disability supports, (as well as, in some instances *not* receiving the supports I need), I have made some suggestions about how supports and services may be improved for people with a disability under a new Life-time Disability Care and Support Scheme.

Most of the problems I have related to my disability supports revolve around the quality and quantity of personal care supports that I receive. I will explain in depth what these problems are and how they could be resolved. I will then also look at some other supports that would improve my quality of life and the quality of life of my family and friends.

Attendant Support

I access the attendant support I need (to assist with things like eating and personal care, accessing my studies at University etc) in two different ways, through an agency as well as by directly employing my own workers. Being able to employ people directly is generally a better option for me because I can choose who I want to have working with me and can feel confident that they will be someone who is competent in the role and whom I can trust. This decreases my anxiety about being left alone with a carer that I do not feel comfortable with, and allows me to feel more confident about replacing carers if they are not suitable.

Additional costs for attendant support - covered by my family

Many times when I employ carers directly, this is financed by my family, as I often don’t have enough support hours to allow me to do all the things I want to do. Particularly if I want to go out and socialize as well as just accessing the support I need for my everyday Uni routine etc. Attendant support is costly, particularly on a weekend -$100 -$200, just for a night out. This means I have little left over for the costs of actually socializing! If I was not living with my parents, paying privately for carers for the sole purpose of socialising would not be financially possible, given the fact that I would have to prioritise costs of living such as food or rent for example.

Funding allocation needs to be in line with the cost of attendant support

I would also like to highlight the lack of compensation for fluctuations in carer payments which are dictated by agencies to some degree. Some time ago, one of my agencies increased its weekend rates and as a result, I lost 4 hours of attendant support. Unfortunately, Victorian Department of Human Services (DHS) did not increase my allocation by offering me more hours. Whilst I agree that carers should be paid a higher rate for working weekend shifts, these wage changes must be compensated by the government body that funds my attendant care support.

I therefore think there should be more generous funding allocations for attendant support.

I would be nice to be able to have enough to enable me to go out as least semi-frequently as well as having hours for everyday support without my family having to cover this expense. It is essential that the government funding given for attendant support services matches the going hourly rate for carers.

Based on a generally successful experience of employing my own carers, ***I would like to strongly suggest that under the scheme, people with disabilities should have the option of being able to directly employ their own carers and be given the funds to meet their needs.***

A shortage of carers and a need to attract younger workers to the field of disability support

Next I would like to point out the issues I face regarding the lack of choice with respect to the attendant care services I receive.

In general, I feel that I am given sufficient choice about which agencies I work with and I feel like I have proper control over what my Independent Support Package (ISP) is used for. However, I definitely do not have enough control over which carers I can employ, due to a significant shortage of carers in the industry. As a general rule, young people such as myself would probably like to have youger carers, particularly when socialising, however this is not always possible, again due to carer shortages.

OH&S requirements compromising care

I have also noticed an increasing number of occupational health and safety issues that have placed more and more restrictions on what carers are allowed to do for their clients. It has come to my attention that carers must now obtain an official qualification to do many of the tasks that they were previously allowed to perform without questions being asked. It also seems to vary in terms of how long it takes for carers to get the relevant qualifications. What this means in practice in my situation is that I am having to ask my parents to do certain things for me such as giving medication, or changing dressings until my carers have been given official permission to perform these tasks. Whilst this is somewhat manageable for the time being, it is my aim to move out of home, and therefore it is absolutely necessary that my carers be allowed to meet all my needs.

Whilst I think that it is good that carers are being forced to obtain a qualification – because the job is then seen as more presdigeous - this should not impact upon the quality of service delivery to people like myself. Prospective carers should be able to start working in the industry without this qualification so long as they obtain it within a given time period.

Access to flexible supports in education

Another issue I would like to highlight is being able to get the support I need at University. Currently the University will provide a 'note-taker' as a scribe in lectures and to assist with other study related tasks. This person is not, however allowed to undertake the personal care duties I need during any normal day at Uni. This means that I have to take preventative medications during the day and this is certainly not good for my health. It also means that I need to have two people providing support for me rather than one. I feel that this is a waste of government resources, particularly in my situation, as one person with all the necessary skills would be perfectly adequate. If this system worked well, it might be able to be carried forward to the workplace.

Again, I think that more generous allocation of attendant support hours under the scheme could assist in solving this problem.

More funding for home and vehicle modifications and fully funded aides and equipment

I would also like to support calls for the cost of aids and equipment for people with disabilities to be covered in full, rather than partially funded as they are currently and for aids and equipment to be able to be accessed as needed.

Under the Victorian Aids and Equipment scheme I become eligible for a new wheelchair (for which I can receive partial funding) every seven years. I am generally in need of a new chair sooner than this. Also, in order to pay for the chair I need, there is a significant amount of money that again, my family needs to pay.

Whenever Mum and Dad by new cars, they need to have a hoist so that they are accessible for me. We have received some funding for this, but not for other modifications such as an air-conditioner that will cool the whole car (I have issues with over-heating, related to my disability). For the cost of an air-conditioner that I need, we sought financial assistance through the local Rotary club. While we were grateful for their help, I don't think people with disabilities should have to rely on charities to pay for the supports we need.

In order to accommodate my access needs, our family home also had to be renovated, including having the house made longer, some of the rooms bigger with wider door frames and a ramp in the backyard. Although we accessed some funding for these home modifications, there was comparatively little financial assistance available and the renovations were an enormous cost.

Everyone deserves a livable home space and for home to be livable for me I need it to be accessible.

I hope that there will be more funding allocated to cover the cost of home and car modifications under the scheme.

Access to supports in employment

I would now like to stress how important it is that young people with disabilities such as myself, are given adequate support in the workplace, irrespective of their field of interest. My aspirations highlight this as I want to have a career in film or television, but I am concerned about some of the problems I might face when working in the industry, that are specifically related to my disability.

A successful artistic career requires some long and irregular hours, which I am prepared to work but for which I fear I will not get the adequate supports, particularly in terms of the quantity of attendant care hours. I also worry about whether the supports will diminish when I am not working on a particular project, as this would significantly diminish my quality of life. I am also highly aware that my potential employers will be unable to pay for the costs of my supports, or will be unwilling to do so. This is why a great number of people with disabilities end up working in the disability sector, because they know that they can have their support needs met. Whilst this is a field I am interested in, it is not my first choice and I would hate to change careers based on convenience rather than a lack of desire to do the job.

Ultimately, my goal is to work overseas in theatre in England. I envisage that I would set up my own theatre company that would perform a teaching and mentoring role for people with disabilities who also wanted to pursue high standard careers in the performing arts. Part of achieving this goal is to study at the Victorian College of the Arts School of Film and Television, however with both of these aspirations, the right supports would be crucial.

At the moment, achieving these two goals feels really daunting, and I am still unsure as to where to start. I am certain however, that it would require 24 hour care, however this is not something that will dissuade me from pursuing what is ultimately my dream job.

I would now like to discuss the importance of the provision other services that have, or would have been useful throughout my life and throughout the lives of my friends and family.

Positive impact of early intervention

I would like to begin by saying that my early intervention had a positive effect on my development as a child, and as a person. I had a lot of physiotherapy and Occupational Therapy which undoubtedly made me a much healthier person than I would have otherwise been. This was often done in the context of a mainstream education which meant that I was often interacting with other children without disabilities, which I feel was important in my social development. It is also possible that I have one of my Occupational Therapists to thank for getting me interested in a creative career, as she was the first one who introduced me to playing music. Who would have thought!

More information and counseling supports for people with disabilities and families

Whilst this is all well and good, I feel that my family was not adequately prepared for what kinds of services I would need as I grew up, and what kinds of challenges we would face. Whilst my parents were proactive in finding the best possible outcomes for me, I now know that this was hard for them and that it would have been a lot easier for them if they had more help to do this.

One of the community supports that has been beneficial for me was counselling with a person who works in my local community health centre. This service has been useful in helping me overcome some of the emotional strains of having a disability. Whilst other members of my family have also seen counsellors at various times in their lives, I feel that more could have been done to assist them in coping with some of the challenges that my disability has presented. In particular, it would have been useful for my whole family and I to have had the option of seeking counselling and mentorship right from the point of diagnosis so that we would have had more of an idea of what to expect, and a better understanding of what each family member was going through.

In addition, I would add that more attendant care funding for people such as myself would ensure that families would not have to cope with the burden of providing the majority of care for their loved one. This in turn and I believe would reduce the stress and emotional pain often suffered by all family members, particularly siblings of people with a disability.

I also strongly support for guidance and counselling for families and people with disabilities alike. More respite would also improve the quality of life of both people with disabilities and the families that care for them.

I am no longer able to get the supports I need

One of the key things that my family and I were not prepared for is the fact that as someone with a disability transitions from high school to university in particular, one's access to services changes due to differences in funding and policy. For instance, my integration funding throughout my pre-tertiary education not only catered for personal care and notetaking assistance in class, but funded extra things like physio which I was able to have once a week. This is no longer provided by the Education Department, or any other government body for that matter, meaning that physio expenses must come out of the expenses of me or my family. This ultimately means that I cannot have it as regularly as I would like. I envisage that this will have a negative impact on my health and well-being in the long term.

I therefore call for a Life-time Care and Support Scheme which ensures continuity of supports throughout the whole life of a person with disability.

Making it easier to enter into disability support system and helping people know what supports they are entitled to

The final issue which I would like to address is related to people with disabilities being able to gain entry into the disability support system. Whilst I have been relatively lucky to get the level of support I have, it is still not enough to live a fully independent life away from my parents, which is also one of my future goals. I have found that the crisis-driven nature of the system has meant that my parents and I have constantly had to fight to receive more services. Much of this ‘fight’ as had to occur because in the disability support system, my case is not yet considered ‘severe’, i.e. my parents are not yet incapable of caring for me. Whilst I do think it is important to delineate between those who need lots, or very little support, families should not have to wait until they are at breaking point to receive adequate support.

On a systemic level, it has also come to my attention that many families and people with disabilities are not aware of the quality and quantity of supports that they may already be entitled to, which often results on their missing out. I feel that more needs to be done to get people actually into the system because most people would say that any support is better than nothing.

My recommendation is that families and people with disabilities should be given more information about the kinds of services they can receive right from the point of diagnosis, and should not be pushed to crisis situations before they are given adequate supports **for the needs of the person with a disability in question.**

To conclude my submission, I would like to say that a Lifetime Care and Support Scheme is vitally important because, if administered and managed correctly, it would mean that people with disabilities like myself could stop worrying about having to fight for essential support services and instead, lead rich and fulfilling lives.

I would like to once again thank the Productivity Commission for reading my submission, as I hope that it will improve not only my life, but the lives of other people with disabilities.